Welcome and introductions

Darrell Foss, the Chairperson, welcomed the group to the meeting with several opening comments, summarized below:

- Now 80 people are engaged in five committees. With staggered starts some committees are close to wrapping up their work, others just gaining traction, yet others have a first meeting on the horizon.

- The work is intense, dependent on the skills and commitment to this effort of each participant, and a wonderful display of people coming together to determine where the state stands in terms of preparedness for the Alzheimer’s tsunami that has arrived in Minnesota and to formulate specific recommendations on what needs to be done in response.

- The Work Group is welcoming two new members:
  - Dan Panoken, consultant affiliated with Care Providers of Minnesota
    - Joining Residential Care Committee
  - Peggy Gaard, Director, Open Circle – Adult Day Services
    - Joining Public Awareness and Risk Reduction Committee

Following Mr. Foss’ remarks, the Minnesota Board on Aging administered the oath to formally appoint Mr. Panoken and Ms. Gaard to the Work Group.

Planning for the future: Roles in report dissemination

Work group members brainstormed their roles in ensuring the report is impactful after it is submitted to the legislature:
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- Alzheimer’s Association Rally Day 2019 Focus on Legislative Report recommendations
- Contact legislators about the report recommendations and ensure they’re focused on Alzheimer’s
- Within government, keep sharing information, keep programs moving, respond to report, and analyze results
- Don’t lose focus on people represented.
- Pay attention to progress on recommendations from 2011 report and 2019 report
- Think about awareness campaigns to build momentum
- Find ways to represent those who don’t/aren’t able to represent themselves
- Be relentless – constantly talk about the issue and report

Cultural Responsiveness and Health Equity Committee Share Out

Presentation from Bruce Thao and Sara Chute

Center for Health Equity, Minnesota Department of Health (MDH)
- For the presentation slides, please see meeting documentation: meeting slides

Sarah and Bruce provided an overview of health equity concepts and the frame MDH is using to approach health equity. Work group members and meeting attendees reflected on the following discussion questions based on the presentation:

What opportunities do aging adults have to define or create their own health?
- Planning around aging – shifting from institutionalized approach to models for independently creating health
- Meeting aging adults where they are – connect and hear their voices
- Improving health literacy can empower aging adults to be self advocates
- Encourage assertiveness – aging adults can negotiate their needs related to living independently
- Caregivers can honor wishes of individuals living with
- Improving mental health and wellbeing can improve overall health

What are they ways that aging adults interact (or do not interact) with nature?
What are the implications for their health?
- How to build dementia friendly communities – we’re not there yet
Person centered planning looks different for all individuals, and allows aging adults to engage with nature in a way that fits them individually.

It becomes harder as you age to develop a connection with nature.

Pets and gardens can increase the quality of life.

Some participants expressed preference for the word environment over nature, as it is more relatable for individuals living in urban areas.

Example of nature/aging related research in Montana

How are aging adults told they belong (or do not belong) in society?

Slow, imperceptible changes related to aging and health.

Stigma of both aging and dementia – such as segregated housing.

Giving Voice Chorus fosters belonging.

Older adults move through space differently and get left out.

Terms and indicators of respect can increase belonging.

Legislative report vs aging – we’re in a fast paced world.

Culturally Responsive Work in Minnesota – table discussions

The committee invited partners who are doing culturally responsive Alzheimer’s and/or dementia work in Minnesota to share with Work Group members and attendees about their work. Each partner hosted a table (either in person or virtually via webinar) and attendees took collaborative notes on their conversation. In addition, two Cultural Responsive committee members hosted a table to continue the conversation about health equity.

Partners were asked to share about the following questions at their table:

1. What’s the purpose of your program or work? (Your mission or elevator speech would be great here.)
2. What communities do you serve?
3. What are some of the specific challenges or barriers faced by the communities you serve? (Or in other words: why does existing programming not serve the needs of your population?)
4. How does your program help address these specific challenges? (In other words: What does it look like for you to provide culturally responsive services or care to communities?)
5. If you had one wish or suggestion for the Alzheimer’s Disease Work Group to consider making a recommendation on, what would that be? (In other words: What policy-level or statewide solutions could positively impact the communities you serve?)
6. And if you have time – consider sharing some of the strengths or assets that are unique to your community!

The following partners hosted discussion tables. Pictures and a brief description of the collaborative notes are included below when available. Several partners provided either program information or responses to the table host questions listed above, which is included in the meeting documentation.

- Yoli Chambers from Centro Tyrone Guzman
- Robbin Frazier from the Alzheimer’s Association and Patty Carlson with their FQHC partners
- Clarence Jones and Sherrie Pugh – continuation of health equity discussion
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- Nancy Lee and Farhiya Farah – Minnesota Board on Aging Dementia Grants and Cultural Consultants;
• Dorothea Harris, Volunteer of America
Racial equity presentation, Dr. Lisa Albrecht

Dr. Albrecht gave the group a brief overview of the concepts of race and equity to build upon the presentation from the Center for Health Equity. Her presentation is summarized at a high level below, with additional terminology provided in the share out packed from the Cultural Responsiveness and Health Equity Committee.

Equity versus Equality

Equality indicates sameness – everyone gets the same thing, regardless of whether it’s fair.

Example: Everyone gets one step to stand on to look over a 6 foot fence, regardless of whether they’re 4’10” or 6’11”. Equality means that everyone gets the same thing, regardless of whether their unique needs are being met.

Equity indicates fairness – everyone get what they need.

Example: Everyone gets what they need to see over the fence – some people may need more than one step to see over the fence, and others may need something entirely different to see over the
Race versus ethnicity

Dr. Albrecht shared that race is a concept that is socially constructed and is not based in biology, culture, geography, or other shared group membership. Race is constructed to artificially divide people and reinforce social hierarchy, with white individuals at the top of the social hierarchy and people of color (African Americans, Latinx, Asian American, Native/Indigenous people).

Ethnicity is a social construct which divides people into social groups based on characteristics such as a shared sense of group membership, values, behavioral patterns, language, religion, political and economic interests, history and ancestral geographical base. Ethnicity shapes a group's culture. For example, the food, language, music, and customs often identify an ethnic group. Everyone has an ethnicity, though many white people today do not identify themselves ethnically. Whether you come from a German background, an Irish background, or a combination of many backgrounds, these ancestral ethnic identities have most likely played a very important role in shaping how you view, interpret, and interact with the world. African American ethnicity is based on the African tribal identity of the person. Obviously, most African American people do not know their ancestral roots. Latino/as often identify ethnically based on their country of origin, e.g. Puerto Rican, Colombian, Mexican, etc. This is similar for Asian Americans, e.g. Vietnamese, Chinese, Japanese, Hmong (Navigating a Diverse World). American Indian ethnicity is based on tribal identification. White/Euro-American ethnicity is tied to ancestor origins, e.g. German American, Irish American, etc.

Systems of Injustice

Dr. Albrecht also shared about systems of injustice, specifically the four major levels of racism, as indicated in the diagram below. She defined justice as “everyone gets firsts before anyone gets seconds,” crediting the definition to Ricardo Levins Morales.
Key findings and emerging recommendations from Cultural Responsiveness and Health Equity Committee

Most Impacted or Marginalized Groups
- Racial/ethnic communities
- LGBT communities
- First Nations tribes, and rural communities
- Low income communities

Most Effected
Policy / Issues / Program
Policy

What makes this a public health issues?

- Dementia and Alzheimer's is a chronic disease and there are population health interventions to manage and the impact of the disease in order to improve the health, safety and quality of life for diverse and underserved communities.

- The burden is significant and growing for both the person living with dementia and their caregiver/care partner. There are interventions (medical and non-medical) that impact the social and economic burden of the disease and caregiving for families, service providers, Medicaid, Medicare, and community supports.

- There needs to be a mechanism for the collection of disaggregated ethnic/racial data by government and healthcare institutions internally to be combined across systems.

- Governmental and Healthcare institutions need to share data with communities.

- Standards need to be set for how success is being measured re: effective ADRD assessment, diagnosis treatment and support for cultural and ethnic communities and Indigenous peoples. The Cultural Responsiveness Committee found some data on “how much” happened, however information is lacking on “how well did we do it?” and “is anyone better off?” What’s truly working for communities?

Issues

- Minnesota's demographic trajectory for aging adults and diverse and underserved communities with health disparities and inequities requires more health care professionals to address the growing demand.

Program

- Race, ethnicity, and culture impact dementia awareness, accurate and timely diagnosis, interventions, care and support. Affordable, high quality care, information and services on culturally appropriate community-based supports are needed to assist diverse community with the highest disparities who are dealing with dementia.

- Fund and create incentives to hire cultural consultants who have completed the state’s MBA Dementia training coursework. Cultural consultants are community assets available to health systems, health clinics, providers, community-based organizations, and state/county health and human services professionals seeking to address the needs of diverse community with the highest disparities who are dealing with dementia.

- All service providers who intend to provide care to cultural ethnic communities must have someone on staff from that community who has completed dementia training or hire a cultural consultant.
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Barriers to:
People and families accessing services?

- Transportation
- Resources (Financial)
- Health Literacy

Providers to providing culturally responsive care?

- Statewide shortages of professionals in practice areas for older adults and patients with dementia.
- Create a pathway for hiring doctors and other medical professionals that have immigrated to the U.S. at a level higher than just Community Health Worker.

Creating a system/policy that leads to more equitable outcomes?

- Create funding and incentives to grow the number of professionals in geriatric practice, with a special focus on an accelerated pathway for hiring doctors and medical professionals that have immigrated to the U.S.

Community groups?

- We include GLBT people as part of the work of this committee. We are aware that not all people will see GLBT people connected to “cultural responsiveness.” However, we believe that many LGBT communities have been historically marginalized by health care institutions (particularly in communities of color, and among older GLBT people).

Decision Makers Who is at the Table and Who is Missing

- While the 2011 report lacked information about cultural/ethnic communities and Indigenous peoples, structures have since been created that should be supported not only financially but in assuring that they are always part of the planning and decision-making processes.

Who is paid/not paid to be at the table?

How do we create structures to compensate communities for their time and engagement in this work? Pay community to participate and share knowledge.

- To increase clinical trial participation of those with the highest health disparities in cultural and ethnic communities and tribes education, trust-building and incentives are needed.
- MBA Dementia Grants is an incubator that has successfully supported programs and research that is positively impacting the ADRD landscape for cultural and ethnic communities and Indigenous peoples.
Who are the allies to help us work with different communities on this issue?

- Community groups serving elders and ethnic communities.

Assessment of Trends and Disparities Committee Share Out

Dr. Steve Waring and Dr. Kirsten Long shared on behalf of the committee. They provided an overview of their emerging recommendations and then hosted a conversation with the Work Group. Additional information regarding the committee's process is included in the Assessment of Trends and Disparities Committee Share Out Packet.

Emerging Recommendations

1. Install Recommendation Tracking System
   Since the 2011 Preparing Minnesota for Alzheimer's Disease Report, we do not believe demonstrable progress has occurred in creating, developing, or leveraging statewide data sources to effectively document trends and disparities in dementia. We recommend that a mechanism is created to track whether and how these recommendations are met following final delivery of the report.

2. Encourage Culturally Aware Data Collection
   Encourage existing and future data sources to improve culturally competent data collection on minority populations including immigrant (Hmong and Somali), Native American/American Indian, rural dwelling, and LGBT individuals in order to identify existing disparities.

3. Improve Overall Quality of Data Collection
   Leverage existing data sources to better understand trends and disparities in dementia in Minnesota.
   a. Consider strengths and weaknesses of existing data sources that provide statewide data on persons with dementia and their caregivers.
   b. Consider other epidemiological studies that may serve as:
      i. Design templates for either future efforts to track dementia trends and disparities; or
      ii. Candidates for "piggybacking" dementia-related questions onto existing cohort studies.
   c. Combine and merge existing data sources to address key questions of interest (e.g., examine the results of changed patterns of care and quality improvement efforts).

4. Leverage Minnesota All Payer Claims Database
Consider the Minnesota All Payer Claims Database (housed and managed by the Minnesota Department of Health) to address several key questions and more fully advance existing studies of dementia in Minnesota. Specifically:

a. Develop a process or mechanism for researchers and others to link individual or family caregiver clinical data with Minnesota All Payer Claims Database records.

b. Collaborate with the University of Minnesota or some other entity to utilize the APCD to address the following questions:
   
i. Building on recent reports commissioned by MDH, use the APCD to examine prevalence of dementia and dementia trends not only by age group, but also by geographic location, race/ethnicity, and gender.

ii. Similarly, examine per person costs for persons with dementia and dementia attributable spending (overall and by cost category) currently and over time by geographic location, race/ethnicity, and gender.

iii. Per point 3.b.i and 3.b.ii, avoidable hospitalizations, psychotropic medication use (and trends in use), long-term services and supports (LTSS), and/or nursing home use/costs should also be reported in any updated Minnesota dementia prevalence and trends report using the APCD.

5. Care Giver Status on Health Records
   Similar to recommendations from the National Academies of Sciences, Engineering, and Medicine (2016), we recommend that caregiving status be considered for inclusion in health records.

6. Synchronize Quality Indicators
   Relying on representative stakeholder groups such as the Minnesota Brain Aging Research Consortium (M-BARC), obtain reports/updates from Minnesota-based health care systems that have implemented programs designed to improve dementia care across their systems to synchronize quality indicators that are able to be implemented across other systems.

Discussion of Assessment of Trends and Disparities Emerging Recommendations

Are there any recommendations that the committee should revisit conceptually?

- Did the committee look at patient-generated data (think social media) as a source of data?
- Has enough emphasis been put on qualitative data sources?
- Re: culturally aware data sources – encourage group to dig deeper into different cultural communities and define what “culturally aware” means in terms of data collection.
- Encourage hiring people from within diverse committees to collect that data.
- Recommendation #1: terrifically important! Thank you!
• Has the committee considered asking various communities of color what data they are interested in related to this topic.

Do any recommendations connect to recommendations emerging from other committees that we should be aware of in terms of shaping the final report?

• Recommendation #6 connects to the work on Diag/Treat/Edu Committee. Academy of Neurology has quality indicator list that may be useful and Minnesota Measurement.

What recommendations are missing?

• Linking tracking of dementia with all other tracking (other chronic conditions, for example). Care planning is jeopardized if cognitive capability of patient is unclear.
• Caregivers aren’t just spouses.
• Recommendation #6 – good data “in” will produce good data “out”.

Collectively, are these recommendations “pitched” at the right level?

• Language is pretty dense – consider using graphics to help readers understand recommendations in final report.

General reminders for all committees

• Watch language - Eliminate use of “minority”
• Take care not to dump different cultures in same bucket – e.g. African Americans share little in common with recent Somalian refugees.
• Foresee many recommendations that will require more robust way of accessing funding if they are to succeed.

Discussion of Work Group process for developing recommendations

What are the values for honing in on the recommendations?

• Health is more than health care
• Sense of belonging
• Lens-conscious
• Be mindful of the report’s audience(s)
• Tie recommendations to audience
• Manageable number of recommendations – hone in on what’s most important?
• Build in measurement
• Advancing equity
What process does the work group want to follow to make its decisions about the final set of recommendations?

The Work Group brainstormed 3 options. Option 2 received the most traction for moving forward.

Decision Process Option 1:

Once all emerging recommendations are made by committees, use a “multi-voting” or dot-voting process (where each work group member and/or the interested public gets X number of votes) to select recommendations.

Decision Process Option 2:

1. Committees rank order their recommendations – overlap across committees gets higher ranking/priority
2. Work Group (or small subsection of people) reviews recommendations, assesses overlap, and “slims” recommendations
   a. Small task group could review committee outputs for overlap and help do some leg work – provide the work group something to react to

Option 2 Pros:

- Committee co-chairs could be engaged in the smaller task group

Option 2 Cons:

- Would each committee have to put forth the same number of recommendations? (fairness concerns)
- Committee co-chairs and work group are already tapped for a lot of work

Decision Process Option 3:

Delegate a menu of options for decision making by an external group to promote buy-in

Next steps:

The Work Group selected option 2, with more focus on a sub-group slimming/aligning recommendations from committees, and a lesser emphasis on committee’s ranking recommendations. Seeking volunteers for a small task group to assist with reviewing emerging recommendations across committees and doing some “leg work” to create draft recommendations for the work group to react to.
How should the work group assess its final set of recommendations?

- Screen recommendations using the cultural responsiveness committee’s framework/lens
- Consider impact, if it’s measureable, and how it can be implemented
- Value among alignment – if a recommendation emerges from several committees, holds more weight
- Consideration of the cost impacts (both positive and negative)
- Clear ownership and buy-in for moving each recommendation forward
- Include those with dementia in the process

Meeting materials for 4/24 Work Group Meeting

- Cultural Responsiveness and Health Equity Committee Share-Out Packet and Emerging Recommendations
- Assessment of Trends and Disparities Share Out Packet and Emerging Recommendations
- Power point slides from meeting, including Center for Health Equity presentation
- Program information from table host partners
- Revised roadmap and charter